WORLD AIDS DAY
FEATURES

No. 1 • 1992

Nongovernmental Organizations — Committed Communities

Nongovernmental organizations (NGOs) — a self-explanatory, if cumbersome name — were among the first groups in society to respond effectively and positively to the threat of AIDS. Where governments were unwilling, unable or slow to step in, they gave vital care and support to people affected by the human immunodeficiency virus (HIV). Effective lobbying by NGOs has helped force the issue firmly onto most national agendas. But whether they are international charities or community support networks, NGOs remain crucial. They are closer to the problem, and the trust they enjoy at the grass roots puts them in a privileged position to help bring about the kind of behaviour change which can thwart the spread of HIV.

As the pandemic develops, the challenge will be for NGOs to coordinate their valuable activities not only with each other, but also with governmental and intergovernmental organizations.

The first NGOs to work on AIDS emerged from gay communities. In the United States, the Gay Men's Health Crisis (GMHC) was in the front line. In London, the Terrence Higgins Trust (THT) - now one of the leading AIDS Service Organizations (ASOs) in the world - was formed by Higgins's lover and other gay men after Higgins died in 1982, the second reported case of AIDS in Britain.

Countless other groups have sprung up since then; among them AIDES in France, and the Swiss AIDS Foundation — whose Hot Rubber Company made condoms a chic accessory for gay men. In the Philippines, Singapore and Thailand, there has been an intense NGO response to the pandemic. Coalitions of NGOs such as the Norwegian AIDS Association bring together a range of groups in successful collaboration. Consortia of NGOs based in Britain, Canada, the Netherlands and the USA, for example, are working together in countries on the other side of the North-South divide. And regional networks linked to the International Council of AIDS Service Organizations (ICASO) — an organization which has received heavy backing from WHO's Global Programme on AIDS (GPA) — have sprung up in Africa, Europe, Latin America, and the Pacific.

Whether they are exclusively ASOs or organizations for which AIDS is only part of their work, NGOs have natural advantages in dealing with issues which many parts of society still find embarrassing. If they emerge from the community they seek to serve, they are inevitably more aware than governments of individual, religious and cultural sensitivities at the community level. They are more likely to be characterized by personal commitment, can be more flexible, and can often publish more explicit material on sexual behaviour than could be sanctioned for an official government campaign.

"NGOs have more commitment than governments. They are more flexible. They don't have to wait for a four-year budget before taking action. ... Of course, that doesn't mean that governments should be allowed to dodge their own responsibilities. I tell them: `they are your people'."

- Father Michel Descombes, Secretary-General, Caritas/Rwanda

"There are clearly a lot of things we can say and do that governments cannot", says Nick Partridge, Chief Executive of THT. For example, a Trust leaflet entitled Safer Sex For Gay Men has an erotic photo of gay oral sex on the cover, and inside — in the strongest possible language — a long list of safe sexual practices which many would regard as exotic.

But the Trust is not dedicated just to the gay community. It now provides welfare, legal help, and counselling to all people affected by HIV and AIDS, including the partners, friends and families of HIV-infected people. In one recent project, the Trust trained a

group of teenage girls as peer educators to take AIDS information into schools and youth clubs.

In the developing world, mission hospitals run by religious organizations and other international NGOs were undoubtedly dealing with the results of HIV infection well before AIDS had been identified. In Zimbabwe, a sudden increase in the incidence of Kaposi sarcoma — a common symptom of AIDS — was registered back in the 1970s. But partly because the developing world has no long tradition of NGOs, and partly because of the way the pandemic has spread, it was several years before any AIDS-specific nongovernmental organizations sprang up within the developing countries themselves.

One of the earliest to emerge was the AIDS Support Organization, TASO, an organized community response to the epidemic in Uganda. It was founded in late 1987 by a group of volunteers led by Noerine Kaleeba, whose husband fell ill with AIDS while studying in England. "The idea of TASO originated from the example of the doctors and nurses who looked after Chris in Britain -- the kindness and care they showed him, despite the fact that he was a foreigner and had AIDS", says Kaleeba. "We were also impressed by the 'buddy' system of counselling we had seen in Britain."

"Buddying"

"Buddying" was developed by gay men's NGOs in the USA and has spread to Europe. It is a service to provide a friend, or "buddy", to people with AIDS who are isolated or need support beyond what can be offered by their friends, partners and family.

Most TASO workers are themselves infected with HIV, demonstrating as their own example the TASO slogan: "Living Positively with AIDS". With offices in Kampala, and in Masaka 80 miles to the southwest, they have provided hundreds of people affected by HIV or AIDS with counselling, information, medical and nursing care, and material assistance. A key factor in the establishment of TASO was the attitude of the Ugandan government. "One cannot rely on government funding, but the government's blessing is necessary", says Kaleeba.

The relationship between NGOs and governments may sometimes be difficult, not least because many NGOs were formed specifically to plug a gap in government services which the statutory authorities may then feel absolved from providing. Governments may quarrel with NGOs over the explicitness of NGO publications, or disagree over the frankness of educational material or media campaigns on AIDS.

"Sometimes it is almost a love-hate relationship", says Bob Grose of GPA, who is responsible for liaison with NGOs. "The reality is that there does need to be a healthy tension, with the NGOs prepared to work with government but at the same time guarding their independence."

Some NGOs have a better relationship with governments than others. Some accept a great deal of government funding. Some refuse any at all. "You need the spectrum from angry advocacy to behind-the-scenes advocacy", says Grose. "In the United States for example, I think there is no doubt that both kinds of advocacy by NGOs, from the AIDS

Nongovernmental Networking

National and international linkages between NGOs are an important part of the global response to AIDS. The Global Programme on AIDS helps them forge these links with advice, expertise and technical backup. Such international NGO networks include:

- the International Council of AIDS Service Organizations (ICASO), and related regional networks, which include EuroCASO, SANASO (the Southern African Network of AIDS Service Organizations), and, since last December in Senegal, WANASO (the West African Network of AIDS Service Organizations);
- the International Steering Committee for People with HIV and AIDS, (ISC), whose regular conferences strengthen and lead to the creation of subgroups and networks in countries around the world;
- the International Lesbian and Gay Association (ILGA), which pre-dates the AIDS era, and which has generated a European networking forum focusing on the anti-AIDS efforts of gay and lesbian communities;
- the Network of Sexwork-Related HIV/AIDS Projects, of which the inaugural meeting took place on 18 July 1992 in Amsterdam;
- the International Federation of Red Cross and Red Crescent Societies which, with its many years of experience in humanitarian and development assistance, is carrying out many AIDS prevention and care activities;
- many other associations, for example those established by religious groups or institutions, women's organizations, student and trade unions.

Action Council to Act Up, have played a part in encouraging the government to be more active and in getting drugs released for trials."

As NGOs proliferate and the incidence of AIDS accelerates, there is a growing need for more cooperation and coordination not only between NGOs and government, but also between NGOs themselves — through NGO coalitions and networks (see box) — and between NGOs, governments and intergovernmental organizations (IGOs).

"NGOs have credibility, access to communities and flexibility, but community-based groups lack authority, money, materials and in many areas they lack management expertise", explains Grose. "Governments have official authority, but many lack knowledge of the grass roots. Intergovernmental organizations can mobilize funds and skills but don't have authority or access to the community. ... This is why you need all these organizations, and why we need to find ways for them to work together."

"It is ... essential that all relevant parties, governmental, intergovernmental, and nongovernmental, forge partnerships to ensure the genuine involvement of community-oriented organizations that are already working on AIDS or that have the potential to do so. This involvement must include participation in the design, implementation, and review of programmes and activities at local, national, regional and global levels. To be successful, such working relationships need to be based on mutual respect between independent partners."

- from WHO's Global Strategy for the Prevention and Control of AIDS, 1992 Update, endorsed by the World Health Assembly on 14 May, 1992

NGOs Around the World

- In Indonesia, the Surabaya Transvestite Association (Perwarkos), began AIDS-related activities in 1988. It stages public entertainment performances aimed at increasing AIDS awareness among transvestites and the general population.
- In Porto Alegre, Brazil, the Support Group for the Prevention of AIDS, together with the Beneficence Society for Prisoners at Presidio Central, produced an explicit educational comic book on AIDS for prisoners. An additional 8000 issues have been published for distribution to other states in the country.
- In Nigeria, an organization called STOPAIDS conducted an educational programme on AIDS to reach truck and bus drivers, passengers and businessmen in two major bus stations in Lagos.
- In the Indian city of Vizianagaram, Andhra Pradesh, a survey conducted by the NEW HOPE Rural Leprosy Trust found total ignorance of AIDS among 1034 of 1365 men questioned. In collaboration with two other NGOs, it hopes to produce an educational magazine called "Brother-in-law" — a name with sexual connotations in the locality.

READEX
FICHE

WORLD AIDS DAY
FEATURES
No.2 • 1992

AIDS Education at School and at Work

Education is vital in the fight against AIDS, and schools and workplaces are excellent arenas in which to inform large numbers of people. "You reach a large audience in environments which can play a very positive role in supporting behaviour change — from teachers, parents and other students on the one hand, or from employers and fellow workers on the other", explains Dr Amir Mehryar, an expert on youth and the general public in the Intervention Development and Support unit of WHO's Global Programme on AIDS (GPA).

Educators hope that information programmes will help to prevent the transmission of HIV, and — by explaining how HIV is not transmitted — to dispel prejudice and discrimination against people with HIV infection and AIDS, both at school and at work

In the Schoolroom

A Ugandan man aged 32 was asked last year if he had changed his sexual behaviour in the light of information about AIDS. "Yes," he replied, he had. "I stopped playing sex with prostitutes. I now use schoolgirls."

This reaction was logical. Prostitutes are indeed more likely than schoolgirls to be infected with HIV. But his answer underlines the growing risks faced by young people in the age of AIDS. It also demonstrates the urgency of teaching them how and why to say "no" or — when they really do want sex — the importance of safer sexual behaviour. "Young schoolgirls may be infected by older men, and schoolboys can then be infected by the schoolgirls", says Dr Mariella Baldo, a GPA colleague of Dr Mehryar.

As many families find it difficult to discuss sexual matters at home — and as AIDS is a subject on which many parents are not informed — the importance of AIDS education in the classroom can scarcely be exaggerated. In many developing countries, more than two thirds of adolescents between the ages of 15 and 19 have had sexual intercourse. At least one fifth of all people with AIDS are in their twenties, and the long latency period of the disease means that most of these were infected with HIV as adolescents. "Programme planners must acknowledge that some students may already be HIV-infected", WHO wrote in a guide produced with the United Nations Educational, Scientific and Cultural Organization (UNESCO) on school health education to prevent AIDS and sexually transmitted diseases (STDs).

Information, values and skills conveyed in schools can have a considerable impact. In Sweden, STDs have virtually disappeared as a result of far-reaching sex education in schools, supported by a high degree of cultural openness about sex, and clinics for young people where contraceptives and counselling are provided confidentially.

The ideal method of introducing education on AIDS is to integrate it into an existing health education curriculum, presenting the subject for the first time at an early age and returning to it in greater detail as the pupils approach sexual maturity. The WHO-UNESCO guide states: "To be effective, education about HIV/STD must be presented within a school health education programme that provides, within the context of local cultural values, a broader understanding of communicable diseases, community health, human relationships, sexuality, drug use, and other relevant issues."

Unfortunately, very few schools in the world have compulsory health education, and in some countries those children who do go to school may leave not at 18, 16 or 14 years of age, but as early as 10.

Dr Baldo has been involved in a WHO/UNESCO joint effort to set up pilot projects on school AIDS education in Africa (Ethiopia, Mauritius, Sierra Leone and United Republic of Tanzania), Latin America (Venezuela and Jamaica) and the Pacific. Although each project has different specific objectives, all aim to introduce AIDS education into the

national school curriculum by training teachers and developing appropriate teaching and learning materials.

"Ideally, a big part of the curriculum should involve learning how to say 'no' to whatever you do not want, and that comes after deciding what you really do want", she says. "If you ask pregnant girls: 'did you want to get pregnant?', most will not say yes."

Opponents of AIDS education in schools have suggested that parents will disapprove or that sex education encourages young people to have sex. Neither theory is true. "Education planners realized in Ethiopia that, despite their own hesitations, parents are supportive of AIDS education in schools, even if it includes aspects of sexuality which were never allowed to be discussed in schools before", says Dr Baldo. "And there is no evidence that early sex education encourages early sexual experimentation. In fact there are indications that the opposite is true."

Resistance to AIDS education often lies with teachers themselves. They may be uncomfortable about presenting sexual issues to the pupils, particularly in societies where the subject is shrouded by taboos. "Young people have fewer inhibitions than adults in talking about sex", Dr Baldo says.

Where teachers are unwilling to talk about AIDS, one solution may be to invite experts from outside into the schools. This can be successful — provided that the teaching extends beyond biomedical facts to social skills and practical methods of AIDS prevention, including condom use. Another solution is peer-group training of the kind being developed in Poland (see box), or the organization of extracurricular activities on AIDS involving the students themselves, possibly related to World AIDS Day.

Finance is often a problem, however. Even successful pilot programmes are of little use unless implemented nationwide. Some developing countries have difficulty finding the funds even to print maths books, which means there is little chance of paying for leaflets on AIDS. It also costs money to train teachers about AIDS. So without external funding, many developing nations do no have the resources to help AIDS education in schools become an integral part of the national curriculum.

Dr Baldo urges governments to give a high priority to AIDS education when formulating and considering aid requests. "It is a crime to deny information on AIDS to young people", she says. "They have the right to know in order to protect themselves. In the age of AIDS, sex is no longer a private matter."

In collaboration with the United Nations Educational, Scientific and Cultural Organization, WHO has developed and published a guide to assist AIDS education in schools. Entitled *School health education to prevent AIDS and sexually transmitted diseases*, it has substantial input from four major teacher organizations, and is aimed at senior educational authorities and people responsible for programme development.

(WHO AIDS Series 10, ISBN 92 4 121010 9 Price: SF 18, or SF 12.60 in developing countries)

In the Workplace

As the vast majority of people with HIV are of working age, AIDS poses a major social and ethical challenge in the field of employment. Many companies have dismissed workers on learning tht they are HIV-positive. Sick leave, pension or disability payments can be expensive, and managers hope to save money and trouble by keeping their firms "AIDS-free". For their part, workers have frequently shunned colleagues with HIV or AIDS, almost certainly unaware that there is no danger of infection.

As far as employment rights are concerned, international conferences have agreed on broad policy principles designed to protect workers with HIV infection or AIDS (see box). The solution to workplace prejudice, and to the accidental transmission of HIV through ignorance, lies in education.

Very few workplaces, apart from brothels, harbour any risk of HIV transmission. Unlike other viruses, HIV is not transmitted through casual contact such as breathing the same air or sharing a lavatory seat. In hospitals, people working in health

AIDS in Schools

Sami Sobie — Ourselves for Ourselves

Since 1988, female students of midwifery aged 18 and 19 have been talking about AIDS to schoolchildren from the age of 11 upwards in and around the Polish city of Wroclaw. Dr Zbigniew Halat, who launched the scheme, was appointed deputy health minister last year. He has helped set up a group called "Sami Sobie" ("Ourselves for Ourselves") which aims to develop the idea nationwide after a summer camp which will train 60 midwifery and nursing students to train their own fellow students as trainers.

"In Poland, doctors are often not very good at AIDS education. They tend to medicalize issues and use words of Greek and Latin origin. And teachers get red faces about condoms. But we have 13000 nursing students at secondary school level — 3000 of them doing midwifery. So we can make an army of health educators who are good at talking about sex to people of their own generation."

care may protect themselves by avoiding direct contact with blood and other potentially infectious bodily fluids.

Certain groups of workers, however, are at particular risk of becoming infected with HIV. In the case of prostitutes, this is due to the nature of their work itself, especially if it involves sexual intercourse without a condom. For other groups, the conditions of work are often the main factor. Some men may have to live at close quarters with other men for months at a time, hundreds of miles from wives or girlfriends at home.

"In centres where there are lots of migrant workers living in hostels — single men living away from home — you find a lot of prostitution", says Dr Mehryar. "And as with prisons and boarding schools, you get men having sex with men."

Mining compounds in South Africa, for example, are encircled by women willing to provide sex for money. High HIV prevalence in Côte d'Ivoire is fanned by the movements of migrant workers employed by the country's international rubber, cocoa and oil companies. And many of the prostitutes servicing such workers are themselves migrants, so the epidemic is fanned further when they become infected with HIV and return home.

In 1991, GPA launched an ambitious programme to prevent the spread of HIV among 10 000 prostitutes and their clients in Abidjan, the capital of Côte d'Ivoire. Prostitute leaders were selected and trained as peer educators promoting AIDS prevention through information and the distribution of condoms — at a profit — in their respective communities. Large companies located close to the sexwork areas were asked to distribute condoms, and there is a possibility of in-company lectures on AIDS being given to workers.

- In Uganda, the Federation of Ugandan Employers (FUE) has implemented a programme on AIDS in the workplace in around 50 of its member companies. More than 240 trainers and 3860 peer educators were trained. An evaluation conducted in October 1991 found a significant rise in condom use and knowledge about AIDS in workers exposed to peer educators and to the AIDS film "It's Not Easy".

- In Latin America, GPA supported an ambitious trade union scheme to tackle AIDS-related discrimination among health care and hospital ancillary workers in Argentina, Brazil, Costa Rica, Curaçao in the Dutch Antilles, and Mexico. The lead partner was the International Federation of Commercial, Clerical, Professional and Technical Employees (FIET).

- In Kinshasa, Zaire, GPA ran a pilot health education project at the Bralima brewery. The eight-month project covered sexually transmitted diseases including AIDS, as well as more general health issues, and evaluators found that it had a marked effect on knowledge levels.

- In India, the United States-based aid agency Family Health International sponsored an education programme directed at clients of sex workers. They included truck drivers, construction workers, port employees, blue-collar workers in private companies, and porters in railway and bus stations.

In April 1990, a congress entitled "AIDS and the Workplace" was organized in Paris by WHO, ILO, UNESCO, the European Community, the Council of Europe, the International Council of Nurses, the Centers for Disease Control (Atlanta, USA) and the labour and health ministries of several European and American countries.

AIDS and the Workplace

In June 1988, in cooperation with the International Labour Office (ILO), WHO held a consultation in Geneva on AIDS and the workplace. Experts from governments, trade unions and employers, from public health, medical, legal and health education sectors, agreed that two principles should guide global policies toward workers with HIV infection and AIDS:

- A worker with HIV infection who is healthy should be treated the same way as any other worker;
- A worker who is ill and HIV-infected (such as a worker with AIDS) should be treated the same as any other worker with an illness.

"Concern about the spread of HIV/AIDS gives employees, employers, labour unions, government agencies, and other organizations an opportunity to create an atmosphere conducive to caring for and promoting the health of all workers. The workplace is an ideal place for educational programmes: such programmes can dispel irrational beliefs and rumours by describng the ways in which HIV infection is transmitted and reassuring employees that there is no risk from seropositive co-workers. Where the risk of HIV transmission is present, chiefly in the medical and laboratory workplace, strict observance of measures to protect employees from exposure to HIV should minimize that risk. In almost all other occupational settings, the risk is close to nonexistent."
(extract from Executive Summary)

WORLD AIDS DAY
FEATURES

No. 3 • 1992

Care in the Community

As AIDS spreads through country after country, government services in the developing world are buckling under the strain. How can all the sick people be treated? Who will look after the AIDS orphans, who may number between 10 and 15 million worldwide by the year 2000? Increasingly, people affected by HIV and AIDS are being helped in their own communities, mainly by aid agencies, religious organizations and grass-root support groups. This is not only through necessity. It is also through choice. Care in the community has advantages of its own.

Many people prefer to be cared for in their own local environment, as opinion surveys have shown. "If they are in the home among the family, the loneliness of hospitalization is removed", explains Dr Margaret Mensah, who works at St Martin's Clinic in the Ghanaian town of Agomanya.

Dr Sandra Anderson, an expert in health-care support with WHO's Global Programme on AIDS (GPA), says that medical care **must** also be provided outside hospitals because neither government nor nongovernmental hospitals can cope with the soaring numbers of people with AIDS and HIV-related diseases.

But community care at its best entails more than the delivery of medical treatment to the homes of people in need. "It means taking a holistic approach — medical, psychological and social", says Dr Anderson. "It means providing support and supplying medicines that help people with AIDS live longer with a bit more comfort."

Children orphaned by AIDS form a major part of the social problem of AIDS. Most experts agree they should be cared for in their own communities if at all possible. Children brought up in distant orphanages find it hard or impossible to reassimilate as adults into the village or urban community in which they were born.

"If anyone wants to help us they should bring their help here, for the whole family", says Lwabuti Luhunge, an 81-year-old grandmother trying to care for her eight grandchildren orphaned by AIDS in the United Republic of Tanzania. "As long as I'm here, why should any of my grandchildren leave home?"

The following two accounts illustrate different kinds of care needed and provided in two African settings. The first community is rural; the second urban. The city project is spearheaded by an international agency motivated by religious belief. In the village that gave rise to the scheme for orphans it was community solidarity.

Among a wilderness of thriving weeds, 14-year-old Veronica and her four brothers and sisters hunt for food on family land now running to seed. They live in the village of Kabonera, in the Rakai district of southwestern Uganda, where already one in eight of all children have lost at least one parent to AIDS.

Veronica has lost both her mother and father, and now she is losing her own childhood in an attempt to hold the family together. "The main difficulty is getting up early in the morning to wake them up", she says. "They won't get up until you call them. And coming back to cook for them and even wash their clothes on Saturday, because they can't wash their clothes for themselves and they can't bathe themselves."

Elsewhere in the village, Josephine, who is in her 60s, is single-handedly raising her 25 orphaned grandchildren. And 15-year-old Semammbo has given up school to look after his dying mother with the help of his brother Charles, four years his junior.

Support for such cases is coming from both inside and outside the community. School fees for Josephine's grandchildren, together with a little basic food, are being provided by an aid agency working through the Orphan Community

Based Organization, OCBO. A local women's group has transformed a former bar into an orphan day centre which gives about 100 children like Charles a place to find friends and emotional support, and the opportunity to make handicraft items for sale or home use. With help from the organization World Vision, the women are also trying to cultivate sweet potatoes and beans for the orphans to eat.

"We thought that we, as mothers, were obliged to look after these orphans, take care of them and teach them what their parents would have taught them if they were alive", says one member of the women's group at a weekly washing session which combines a concern for hygiene with a chance to find out how the children are getting on at home.

"When we saw the children were suffering a lot, we got an idea and opened up a small school for them; and that's been difficult because we had to rent the house and pay the teacher", says another. "We got an organization to support us, but it is still a problem because the number of children goes up every day."

Even without money for furniture, books or writing paper, the women's school gives a chance of basic education to orphans forced to drop out of school because they cannot afford school fees.

Healthcare comes in the form of a mobile team led by Sister Ursula Sharpe and her nursing co-workers of St Joseph's Hospital in Kitovu, in the adjacent district of Masaka. Sister Ursula does her best to stave off AIDS deaths and the consequent orphanhood, and explains how much can be achieved with low-cost medicine.

"I've seen many, many patients before they die and ... their real concern was for the children", she says. "Why should a child watch its parent die from diarrhoea when a very simple medicine can stop it? Why should a child see its father or mother scratching themselves to death? Why should they see such an undignified end to their father and mother when simple drugs can keep them alive? So I feel very strongly, let us keep these children from being orphaned for as long as possible."

"In the past, in the African culture, there was no orphan, because a child belonged to the community, a child belonged to the clan. Even if a father died or a mother died, a next-of-kin took over the responsibility of caring for that family", says Moses Ddombo, who works in Uganda for the charity World Vision. "Today, however, that situation is changing. So many people have died in such a short time ..."

Father Michel Descombes, a 70-year-old priest, has lived for nearly 40 years in Rwanda, which is struggling under the effects of poverty, drought, political upheaval, war refugees - and now AIDS. Nearly a third of the women in Rwandan cities are infected with HIV. In the capital Kigali alone, there are 4600 known orphans, and the figure rises every day.

As Secretary-General in the Rwanda branch of Caritas, a Roman Catholic organization, Father Descombes heads a nationwide network of aid bureaux which offer care and compassion to the unfortunate, whatever their need and religious persuasion. In Kigali, his team, which includes Rwandan social workers, offers help to people affected by HIV and AIDS.

"We offer social, even psychological help", he says. "We help with basic medicines, and we help with burials. We try to help people keep their dignity until they die, and to ensure that they are buried with dignity. But then the children are left." The fact that Father Descombes and his team openly visit and care for people with HIV and AIDS helps break down fear and prejudice within the rest of the community.

When it is clear that a woman is dying of AIDS, one of the social workers will begin to supervise her orphans-to-be. In the disintegrating family structures common in urban settings, fathers are often absent from the scene, and the presence of someone with an interest in her children can be of great comfort to the mother. The social worker will also begin to seek out relatives able to look after the children following their mother's death.

In about one fifth of the cases, the children can be placed with other branches of their family. In other cases, they may be fostered by elderly women whose families have grown up. And where the oldest child is at least 15 or 16, the social workers help the orphaned children to stay where they are and ask a neighbour to lend assistance. When they cannot remain in their own home, Caritas will provide another. "We try to keep these homes within the community, so that the children can grow up within a social web", says Father Descombes. "We do not want to make ghettos."

For other orphans, Caritas has launched a successful new fostering scheme involving single mothers, with perhaps two children, who no longer want to seek a husband. "We buy the women a house and give them perhaps seven or eight more children to foster, keeping brothers and sister together", says the tireless priest. Caritas pays the women a monthly allowance, and the social workers supply assistance and moral support.

Father Descombes dislikes the idea of orphanages, although he fears they may become necessary as the number of orphans soars. "Apart from the fact that they would cost a lot, these children need the love of a mother. They have special needs. They have watched their mother die", he says. "If we continue to receive help, we will continue to open houses like these. It would be easier to leave the children in the streets. But then they would become little thieves and be housed by the prison service."

Father Descombes, Sister Ursula, the women of Kabonera and many others unlisted are doing invaluable work, but the dedication of a few individuals — even when backed by large organizations — cannot possibly address the scale of the pandemic as AIDS deaths multiply over the coming years.

"Small efforts headed by saints are the models, but they are not enough", says Dr Anderson. "The health-care and social welfare systems, and their workers, must be involved, and governments and nongovernmental organizations (NGOs) must coordinate their efforts."

The challenge is to create an integrated structure embracing national authorities, regional hospitals and NGOs in a pyramidal structure of care based firmly in the local community.

Last year, WHO and the Commonwealth Secretariat held a workshop in Entebbe, Uganda, on community-based care and control of HIV and AIDS. Attended by participants from Ghana, Kenya, Malawi, Nigeria, Uganda, United Republic of Tanzania, Zambia and Zimbabwe, it was followed in March 1992 by a similar event in Kigali attended by participants from French-speaking African countries: Burkina Faso, Burundi, Cameroon, Central African Republic, Congo, Côte d'Ivoire, Rwanda and Zaire.

Both workshops aimed, as one of their objectives, to reinforce cooperation between governments and NGOs in order to develop care at the local level. "But community care means different things in different cultures", Dr Anderson stresses. "Something that works in Uganda might work in Rwanda and Tanzania, but it may not be applicable in the same way in Thailand, for example. The national, regional and global AIDS programmes have to assist countries to work out their own model."

"It is very important that external assistance, even from indigenous NGOs, provides the kinds of inputs which support community coping mechanisms and do not undermine them. Families and communities need to be empowered and not made dependent on hand-outs from well-meaning agencies."

from GPA: The Care and Support of Children of HIV-infected Parents

Some material in this article is drawn from a video entitled "The Orphan Generation" and a series of booklets entitled Strategies for Hope. The booklets describe practical action taken against AIDS by all sections of society, and cover projects in Ghana, Uganda, United Republic of Tanzania, and Zambia. Like the video, they are available free or at low cost from: TALC, P.O. Box 49, St Albans, Herts AL1 4AX, UK.

Together with the Ugandan Ministry of Health, UNICEF, and TASO — a remarkable AIDS support organization founded by volunteers in Uganda in 1987 — WHO has produced a practical illustrated care manual entitled Living with AIDS in the Community.

WORLD AIDS DAY
FEATURES

No. 4 • 1992

AIDS: a Challenge to Science and Industry

"The AIDS pandemic is growing by leaps and bounds, making it especially urgent that drugs should be available to care for the millions already infected with HIV, as well as vaccines to prevent spread to the many millions as yet uninfected."
Hiroshi Nakajima, M.D., Ph.D.
Director-General of WHO

More than a decade after AIDS was first identified, scientists worldwide are still grappling with the human immunodeficiency virus in the race to find a vaccine and a cure. Drugs for treating AIDS have been developed, but they are expensive and can alleviate the condition for only a limited time. Yet progress is being made, and experts believe they have real grounds to believe there could be a "silver bullet" over the horizon.

"This virus is very clever; it changes all the time", says Dr Alan Stone, head of the AIDS Secretariat at Britain's Medical Research Council. "And every time we think we are moving forwards it turns out to be not quite as big a step as we thought. ...There are many things we do not understand. Nevertheless, there is a lot of evidence which leads us to think that we will find a vaccine."

The Secretariat, launched in 1987, is responsible for coordinating all British research into AIDS; from directed programmes designed to develop vaccines and new drugs to strategic programmes covering such fields as epidemiological research, sero-surveillance, and clinical trials. But in the urgent quest to save millions of lives, there is a great deal of international cooperation.

"We have very strong links with industry, and internationally with the USA and France, because it is a global activity, and a fast-moving area involving the spending of public money", he explains. "We have all kinds of cooperative agreements with industry: international coordinating committees, for example, on which drug companies are represented at a fairly senior level."

WHO's Global Programme on AIDS (GPA), which has led the world's fight against AIDS since 1987, helps to coordinate such international collaboration on vaccine research and promotes the development of appropriate vaccines for developing countries.

The WHO strategy for AIDS vaccine development — the ultimate goal of which is the development of universally accessible preventive vaccines — considers three potential types of HIV vaccine:

- Preventive vaccines to protect uninfected people against HIV;
- Therapeutic vaccines to stop or delay the progression from HIV infection to AIDS. Such vaccines, the use of which is sometimes called active immunotherapy, might also reduce the amount of virus in infected people, thus reducing the potential for HIV transmission to others;
- Perinatal vaccines to prevent the transmission of HIV from a woman to her fetus or newborn child.

Initial attempts to develop potential HIV vaccines were hindered by a number of obstacles, primarily the failure of experimental vaccines to protect animals from HIV infection. Recently, however, the successful protection of chimpanzees against HIV and macaque monkeys against simian immunodeficiency virus (SIV), a retrovirus related to HIV, has been achieved, and there is now a general consensus that a vaccine suitable for preventing HIV infection in humans could be developed within ten years.

"To predict when we might have a vaccine for general public health use is very difficult, but, being optimistic, I would hope by the end of this decade. Until then, the only effective `vaccine' we have is education about how to prevent transmission."
Dr Michael H. Merson, Director, GPA

As far as treatment is concerned, more than 150 different drugs have been, or are being, developed against HIV infection and the opportunistic infections associated with AIDS. Two drugs have already been licensed, AZT (zidovudine) and ddI (dideoxyinosine) - and a third, ddC (dideoxycytidine), is expected to be licensed soon.

Scientists have high hopes for "cocktails" of drugs. "The goal is to have combination therapy in which drugs would act at different sites in the pathogenesis of HIV infection", says

Dr Michael H. Merson, Director of GPA. "This would probably involve less toxicity and less resistance than a single drug developed to achieve the same results. The problem of course will be affordability, and we hope to continue working with industry to find ways of making any effective drugs and vaccines available to developing countries with extremely limited resources."

GPA holds regular meetings with the International Federation of Pharmaceutical Manufacturers Associations (IFPMA) in pursuit of this goal. Margaret Cone, Vice-President for Scientific Affairs at IFPMA, admits there could be enormous problems if and when a new preventive or curative drug is developed. "It could be politically very difficult if the developed world is seen to have a cure and developing countries are left out in the cold." But she says the pharmaceutical industry is not going to supply drugs to the developing world without making a profit. "If companies are going to invest enormous sums to develop a vaccine, they have got to get a good return on their investment. And an AIDS vaccine is not going to be cheap. The manufacturing procedure is likely to be long, complicated and expensive."

Dr Stone makes the point that even expensive vaccines will be cheaper than drugs. "How are you going to treat people in countries with health budgets of three dollars per head when AZT costs $3000 per year per person?", he asks. "The simple answer is that they are not going to be treated. Therefore the obvious response is that we are going to need a vaccine. And even if that is somewhat expensive, it will be cheaper than AZT."

Whatever the price, most developing countries will not be able to afford universal vaccination without help from the developed world. "The only argument that is going to win the day is to persuade developed countries that it would be more expensive for them NOT to fund vaccination in the developing world", says Ms Cone. "The AIDS issue has got to be seen not just as a health issue, but as a development issue." "It will depend on organizations like the World Bank", says Dr Stone.

An interview with Dr David Heymann, chief of research at GPA

GPA's Office of Research coordinates, supports and promotes biomedical research aimed at finding and developing effective and economical drugs and vaccines for the prevention and treatment of HIV infection and AIDS. It has 20 professional staff in Geneva and employs consultants around the world, mainly in developing nations. From an annual budget of around US$ 7.5 million dollars (excluding staff costs), nearly two-thirds is spent on direct support to research activities.

The office is headed by Dr David Heymann, a medical epidemiologist and specialist in infectious diseases and tropical medicine. Dr Heymann worked for WHO in 1974-75 on the smallpox eradication programme in India before joining the Centers for Disease Control (CDC) in Atlanta, Georgia, USA, to work on childhood diseases. From 1976 he spent 13 years in Africa conducting research for the CDC on childhood vaccine-preventable diseases and malaria. Joining GPA to set up the epidemiology research unit in 1989, he took on his present job in 1990. Here he answers some questions:

In what ways is AIDS particularly challenging or different?

AIDS is a research challenge for many different reasons. The human immunodeficiency virus is a retrovirus which has the ability to incorporate itself into human genetic material and can remain latent - and invisible - for many years after infection. Then there is the stigma often associated with infection because the virus is sexually transmitted: this calls for assurance that there is no discrimination against people participating in research. A further challenge is the despair of individuals who are infected, making them willing or eager to participate in research on drugs or therapies which may lack scientific credibility. Finally, we hope that one day there will be a safe vaccine to study for effectiveness, but this will require the participation of both industrialized and developing countries around the world — a mighty challenge.

What are your main areas of enquiry?

The Office of Research has four scientific units: Vaccine Development; Clinical Research and Drug Development; Diagnostics; and Epidemiological Research and Forecasting. All four do very important work. The vaccine unit is working to reinforce institutions and scientists in developing countries to ensure that they will be able to participate on an equal footing in the testing of experimental HIV vaccines appropriate for those countries. The clinical researchers are investigating how HIV infection develops, and how the associated diseases, such as tuberculosis and fungus infections, can be alleviated by different drugs in developing countries. The epidemiologists are looking into the risk factors for HIV — for fetuses and suckling infants of infected mothers, and adolescents and adults with other sexually transmitted diseases such as syphilis. And in diagnostics, we are trying to develop the best and most cost-effective ways to test for HIV in developing countries.

Your office deals, then with biomedical research. What about social and behavioural research?

GPA's unit for Social and Behavioural Studies and Support is located in the Office of Intervention Development and Support, so that these research activities are as relevant as possible to interventions aimed at AIDS prevention and care. In addition to research on risk behaviour and on individual and community mechanisms of coping with the pandemic, the SSB unit is focusing on social and behavioural issues connected with AIDS vaccine trials. This calls for close collaboration with the Office of Research.

How big a role does cost play?

Cost-effectiveness is one of our highes. priorities. A major GPA research concern — and one we discuss regularly in our collaboration with drug manufacturers — is the development and adaptation of drugs to make them appropriate for developing countries at an affordable price. Our research on HIV testing, by the way, has shown that two or three simple tests costing less than one dollar each are as effective as the "Western blot" test which costs US$ 40. (See Global AIDSnews 1992, No. 1, page 13.) This will save national AIDS programmes large sums of money for diagnosing HIV infection and AIDS, and those savings can then be passed on to other activities. Countries can now buy these simple tests through WHO at the lowest possible prices.

What about other general priorities?

We think it is vital to develop the ability of countries to conduct research themselves. That is why each of our research grants provides equipment, training and the supplies needed to reinforce national institutions and their scientists. We keep a data base of AIDS-related studies in developing countries as well, to identify potential research gaps.

Could you give an example of a specific high-priority research project now in progress?

We are engaged on potentially very important research through which we hope to identify or develop a vaginal virucide. As some men refuse to wear condoms, even where they are available, it would be a real breakthrough if women could protect themselves from HIV infection by the application of a vaginal cream or jelly. Safety tests are under way of a spermicide — developed by one manufacturer back in the 1940s and still on the market — which has been shown in the laboratory to have virucidal properties. But first we have to ensure that the product does not damage the wall of the woman's vagina, as that could actually make HIV transmission easier. That may be a danger with this product, especially as some women would need to use multiple doses per day. We are already working with another manufacturer to develop a specifically-designed vaginal virucide which would kill the human immunodeficiency virus and have less potential for damaging the vaginal wall.

What about vaccines?

Of course, the development of a vaccine is one of the biggest priorities. It is also a challenge because with HIV, different countries may need different vaccines simply because the virus strains are different. Fourteen vaccines are now being studied for safety in volunteers in the industrialized world after which they will be studied for efficacy in these same countries. We are readying the ground for trials of some of these vaccines in developing countries as well once the safety studies are complete. If countries decide to take part in field studies of therapeutic vaccines — that is, vaccines to use in persons who are already infected which could possibly slow their progression to AIDS — then testing might be possible from the end of this year or early next year. As far as

Activities of GPA's Office of Research include:

- Drug and vaccine research coordination to identify the best ways to treat and prevent HIV/AIDS in developing countries;
- Clinical research to achieve a better understanding of the evolution of HIV infection in developing countries;
- Epidemiological research into the modes of HIV transmission, the extent of the HIV/AIDS pandemic and its future demographic impact;
- Diagnostics research to develop the best testing methods for use in developing countries;
- Collaboration with the Council for International Organizations of Medical Sciences on guidelines for biomedical research on humans, to take into account special ethical, social and legal issues surrounding HIV/AIDS and vaccine/drug development programmes;
- Discussions with the International Federation of Pharmaceutical Manufacturers Associations (IFPMA) aimed at ensuring the availability of safe, effective and affordable drugs, and ultimately vaccines, within developing countries.

preventive vaccines are concerned — and I should stress that the development of preventive vaccines is our long-term priority even though this might prove impossible — it may still be two or three years before such vaccines are ready for field-testing in developing countries.

How are you preparing the ground for possible field trials of preventive vaccines?

If it is two or three years to field-testing, then we have time to conduct lots of important research. We have to understand, for example, how to motivate people to participate in trials without abandoning precautions against HIV. We also need to encourage vaccine manufacturers to develop vaccines that are thermostable — that do not require refrigerated transport or storage, and are therefore suitable for tropical countries — and that are effective with one dose, or a small primary series of doses, without a booster. On vaccines and drugs, our research studies are just beginning. But we are confident they will eventually bring the answers necessary for appropriate interventions to prevent and treat HIV/AIDS in developing countries.

(This is a shortened version of an interview given by Dr Heymann to Global AIDSnews, a quarterly publication of GPA.)

The Long Road To Approval

In the USA, new medicines must go through the following procedures before approval:

Preclinical Testing: Laboratory and animal studies to test safety and show biological activity against the targeted disease (about three and a half years);

Phase I Clinical Trials: Tests involving between 20 and 80 healthy volunteers to study safe dosage levels and determine how a drug is absorbed, circulated, metabolized and excreted (about one year);

Phase II Clinical Trials: Controlled studies of between 100 and 300 volunteers with the disease to assess effectiveness (about two years);

Phase III Clinical trials: A phase involving 1000 to 3000 patients in clinics and hospitals (about three years);

Phases II and III may be combined to speed the process for medicines which show sufficient promise in early testing and are targeted against life-threatening diseases.

Source: United States Pharmaceutical Manufacturers Association (USPMA) USA

"The gravity, scope and accelerating spread of the AIDS pandemic cannot be overstated. ... For drug regulators the responsibility lies in balancing the needs of individuals and the needs of society, by expediting the licensing of new HIV/AIDS drugs and vaccines that have been shown to be safe and effective, while ensuring that their scientific evaluation meets the highest technical and ethical standards."
Hiroshima Nakajima, M.D., Ph.D.
Director-General of WHO

Questions Answered:

What is HIV?

HIV, the human immunodeficiency virus which leads to AIDS, is one of a group of viruses known as retroviruses. The genetic information of retroviruses is coded in the form of ribonucleic acid (RNA).

How is HIV transmitted?

HIV infection occurs primarily through anal, vaginal and oral sex. In common with some other sexually transmitted diseases, it can also be transmitted through blood, blood products, donated organs or semen, and from a woman to her fetus or breast-fed infant.

How does HIV operate?

HIV invades human cells by attaching itself to a receptor present on the surface of some cells. One of the main types of cell with these CD4 receptors is a white blood cell called the T-helper lymphocyte. Frequently known as CD4+ or T4 cells, these lymphocytes play a crucial role in the body's natural defences, or immune system. Some other white blood cells and a type of brain cell also have CD4 receptors. Once inside these cells, HIV sheds its protein coat and converts its genetic code from RNA to deoxyribonucleic acid (DNA) by using an enzyme called reverse transcriptase. The DNA produced by the virus is then incorporated into the cell's own DNA, and — when the human cell reproduces — new HIV proteins and nucleic acids may be produced and assembled into new viruses.

How do people know they are infected?

Some people may suffer flu-like symptoms for a week or two, but otherwise, the initial infection usually goes unnoticed. The virus may remain dormant for many years, though the presence of the virus can be detected after about three months by testing for HIV antibodies in the blood. Once the virus becomes more active, and more T-cells are disabled, the body's immune system is less able to resist illness and the person is likely to suffer a series of "opportunistic" infections. In developing countries, the most important opportunistic infection is tuberculosis.